

Assembly Joint Resolution

No. 28

Introduced by Assembly Member Brown
(Coauthors: Assembly Members Bradford, Hall, Holden,
Jones-Sawyer, Mitchell, and Weber)
(Coauthor: Senator Wright)

July 3, 2013

Assembly Joint Resolution No. 28—Relative to Sickle Cell Anemia Awareness Month.

LEGISLATIVE COUNSEL’S DIGEST

AJR 28, as introduced, Brown. Sickle Cell Anemia Awareness Month.

This measure would recognize the month of September 2013, and each September thereafter, as Sickle Cell Anemia Awareness Month in California, and would urge the Congress of the United States to support the President’s continuation of funding for sickle cell anemia centers and research and to make sickle cell anemia and other genetic hemoglobin disorders a public health priority.

Fiscal committee: no.

- 1 WHEREAS, Sickle cell anemia and sickle cell disease, used
- 2 interchangeably, refer to a group of inherited disorders that affect
- 3 the red blood cells; and
- 4 WHEREAS, Sickle cell anemia is a disease in which a person’s
- 5 body produces abnormally shaped red blood cells that resemble a
- 6 crescent or sickle, and which do not last as long as normal round
- 7 red blood cells, which leads to anemia. The sickle cells also get
- 8 stuck in blood vessels and block blood flow, which can cause pain
- 9 and organ damage; and

1 WHEREAS, Sickle cell anemia is a genetic disorder where
2 individuals with the disease are born with two sickle cell genes,
3 each inherited from one parent. An individual with only one sickle
4 cell gene has a “sickle cell trait,” which occurs in one out of every
5 12 African Americans and in one out of every 100 Latinos in the
6 United States; and

7 WHEREAS, Unlike most people with sickle cell anemia, most
8 people who have a sickle cell trait never know they have it and
9 can live their entire lives without any complications from it; and

10 WHEREAS, Serious problems associated with a sickle cell trait
11 are rare. However, exercise-related sudden death in individuals
12 who have a sickle cell trait most commonly occurs in those
13 undergoing intense physical exertion, such as military recruits in
14 basic training and athletes during conditioning workouts; and

15 WHEREAS, Individuals with a sickle cell trait should not be
16 excluded from physical activity, including sports, unless
17 recommended to by medical personnel. Instead, people should be
18 educated about precautions that should be taken, including drinking
19 adequate amounts of fluids, pacing training with longer periods
20 of rest and recovery, avoiding participation in performance tests
21 such as sprints and mile runs, and, most importantly, being familiar
22 with the symptoms of overexertion; and

23 WHEREAS, It is estimated that more than 90,000 Americans
24 have sickle cell anemia. Sickle cell anemia occurs in one out of
25 every 500 African American births and in one out of every 36,000
26 Latino births; and

27 WHEREAS, Sickle cell anemia can be a life-threatening
28 condition, and access to comprehensive care can be limited by
29 social, economic, cultural, and geographic barriers; and

30 WHEREAS, The average cost of hospitalization for sickle cell
31 anemia in 2004 was \$6,223, for more than 84,000 hospital
32 admissions that year. Total hospitalization costs for individuals
33 with sickle cell anemia equaled \$488,000,000, of which 65 percent
34 were covered by Medicaid funds; and

35 WHEREAS, Individuals living with sickle cell anemia encounter
36 barriers to obtaining quality care and improving their quality of
37 life. These barriers include limitations in geographic access to
38 comprehensive care, the varied use of effective treatments, the
39 high reliance on emergency departments and on public health
40 programs, and the limited number of health care providers with

1 knowledge and experience to manage and treat sickle cell anemia;
2 and

3 WHEREAS, The Sickle Cell Anemia Control Act was signed
4 into law in 1972 by President Richard Nixon after pledging that
5 his administration would “reverse the record of neglect on the
6 dreaded disease” by increasing funding for and expanding sickle
7 cell anemia-related programs, including the development of
8 comprehensive sickle cell anemia centers; and

9 WHEREAS, In 1975, the Sickle Cell Disease Association of
10 America, Inc. and its member organizations began conducting
11 monthlong events in September to call attention to sickle cell
12 anemia and the need to address the problem at national and local
13 levels, and chose September as National Sickle Cell Awareness
14 Month in order for the public to reflect on the children and adults
15 whose lives, education, and careers have been affected by this
16 disease; and

17 WHEREAS, In 2003, the Sickle Cell Treatment Act was signed
18 into law; and

19 WHEREAS, The effort to officially recognize Sickle Cell
20 Anemia Awareness Month succeeded at the federal level in 1983
21 when the United States House of Representatives unanimously
22 passed, and President Ronald Reagan signed, the first resolution
23 introduced by the Congressional Black Caucus that recognized
24 September as National Sickle Cell Anemia Awareness Month;
25 now, therefore, be it

26 *Resolved by the Assembly and the Senate of the State of*
27 *California, jointly,* That the Legislature recognizes September
28 2013, and each September thereafter, as Sickle Cell Anemia
29 Awareness Month; and be it further

30 *Resolved,* That the Legislature urges the Congress of the United
31 States to support the President’s continuation of funding for the
32 Sickle Cell Disease Treatment Demonstration Program, the
33 Registry and Surveillance System for Hemoglobinopathy Program
34 Initiative, and the Public Health Approach Disorders program, and
35 to make sickle cell anemia and other genetic hemoglobin disorders
36 a public health priority; and be it further

37 *Resolved,* That the Chief Clerk of the Assembly transmit copies
38 of this resolution to the President and Vice President of the United
39 States, the Speaker of the United States House of Representatives,
40 the President pro Tempore of the United States Senate, each

- 1 Senator and Representative from California in the Congress of the
- 2 United States, and to the author for appropriate distribution.

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